TERMINAL CANCER PATIENT NEEDS

AND

CONTRIBUTION AND LIMITATIONS

OF

THE UNDERGRADUATE MEDICAL PROGRAM IN UNIVERSITY OF HONG KONG

TO DOCTOR'S ABILITY IN MANAGING TERMINAL CANCER PATIENTS

CHAN KAM CHUEN

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I. ABSTRACT

Care of terminal cancer patient becomes more important because of the increased incidence of death caused by cancer. These patients have various aspect of needs. These include symptom control, financial assistance, spiritual need, legal information, social support, psychological needs and effective communications. The medical program in University of Hong Kong both contributes to and limits doctors' ability in managing terminal cancer patient.

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II. INTRODUCTION

In recent years, cancer becomes one of the major causes of death in Hong Kong. (1) Due to this fact, caring for 'terminal cancer patients' (will be defined) inevitably becomes part of a medical doctor's job. In view of this, I think it is the right time to evaluate the actual needs of these terminal cancer patient, and the contribution and limitation that have been made by the undergraduate medical program in the University of Hong Kong (medical program in short) to doctors' ability in managing terminal cancer patient.

In this report, the method used in this study, definition of terminal cancer patient, needs of terminal cancer patient, contribution and limitation of the medical program on this aspect and a conclusion will be presented sequentially.

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III. METHOD OF STUDY

Library study and interview had been employed.

Library studies contributed mostly on understanding the needs of the terminal cancer patient.

Interview was qualitative and its main purpose was to collect more opinion on needs of terminal cancer patient and, of greater importance, on the contribution and limitations of the medical program. The guidelines of questions asked in the interview can be found in Appendix I. Five doctors and one senior medical student had been interviewed. All the interviews were done in collaboration with Mr. Fung Chiu Fai. All relevant opinions gathered from the interview will be integrated and presented in this report. Quantitative analysis is not performed because of small number of students.

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IV. DEFINITION OF 'TERMINAL CANCER PATIENT'

In this report, this term adopts the definition used by most interviewees as patient who is diagnosed to have cancer, his condition is deteriorating quickly, he is bedridden and there is no available active treatment to the patient or he is unresponsible to the active treatment or all active treatment has been withhold for the benefit of the patient. In the remaining part of this report, 'terminal patient' will be used in short.

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V. NEEDS OF TERMINAL CANCER PATIENT

In order to facilitate the presentation, needs of terminal patient is being categorized under a few titles. However, they are by no means independent of each other. In fact, some of them are so related that without caring one of them, the others will not be satisfied completely. Moreover, the needs of every terminal patient will not be identical and hence in tailoring a caring program for a terminal patient, personal factors such as personality etc, should be taken into account. Furthermore, provision of terminal care is not solely the responsibility of doctors but rather a multidisciplinary matters. (2)

(i) SYMPTOMS TREATMENT

For terminal patient to have highest quality of life possible, they must be kept as free as possible from unpleasant symptoms.

Control of pain is of particular importance. However, pain-killing does not just near giving drugs around the clock. The identification of etiology of the pain is also of importance. For the pain may not be caused by the cancer and psychological problem actually plays an important part in sensation. As suggested by an interviewee, patients who are visited frequently by their family members require lesser analgesic than those who are not being visited frequently. A stumbling block to control pain is fear

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of addiction. However, in recent finding, high doses of powerful opiates are frequently indicated, and can be used effectively (for years if necessary) with out unmanagable tolerance or side effects, and without addiction. (3)

Other symptom control such as draining the foul smelling pus, prescribing chemotherapy for bulk reduction of tumous, just to none a few, are also of great use. However, the symptom control should be done in a balanced manner as to allow the patient an agreeable extent of automony and alertness, and live as normal as possible. (4)

(ii) FINANCIAL ASSISTANCE

Financial problems often cause patient unable to get suitable care and frequently impose a certain amount of psychological burden upon the patient. This problem is of particular significance if the chief bread-winner of the family is the patient. Although helping patient on financial aspect may not be within the scope of work of a doctor, he should at least realize the patient's need and, if possible, mobilize the appropriate resources for the patient.

(iii) SPIRITUAL NEEDS

As a person has to face death, spiritual issues - like the meaning of life - naturally arises. In order to satisfy this need, one may require training in philosophy and religious. Although this is usually the work of a chaplain, doctor should be as well prepare as possible or should as least know the correct channel

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where the patient can turn to for answers of these kind of questions. (5)

(iv) LEGAL INFORMATION

Providing legal information to patient or his family occasionally require some attention of a doctor, especially when the patient would like to live at home. If family members understand the procedures they should do after the patient's death, unnecessary anxiety of a postmortem, which most of the Chinese dislike can be erased. For if a person died before he arrives the hospital, a postmortem may be required to investigate the cause of death.

(v) SOCIAL SUPPORT

Terminal patient suffers many losses - all he loves, all that has meant anything to them and ultimately, himself. Hence it is easy to have a sense of isolation, especially if the communications between patient and his family is not good. (6) This makes social support an important aspect of terminal care as well. This can be achieved by reassurance from the doctors that are supportive treatment will be continued and also by the kind attitude shown by doctors. By this, the sense of being abandon can also be erased.

(vi) PSYCHOLOGICAL NEEDS

As proposed by Elizabeth Küber Ross, terminal patient often go through a few psychological stages before he can come to the final stage of acceptance of his death. (7) In order to give the terminal patient highest quality of life,

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beside symptom control, helping him to attain this stage of acceptance is of equal importance. Moreover, the lose of self-esteem due to not the inability to take care of himself, the feeling that he is being a burden to others etc, all create emotional and psychological problems . Hence, counselling becomes essential in the care of terminal patient.

(vii) COMMUNICATION

I set communication report as a need of terminal patient because I think this is actually a bridge to fulfil all other needs of the patient. These communication can be verbal or non-verbal. With good communication between the patient and doctor, as in effective conveying of diagnosis, pronosis and treatment to patient, can clear a lot of uncertainty of the patient and can also helps the patient to accept his imminent death.

From various studies, it has been shown that freedom of discussion and openness helped them to ventilate fears and anxiety caused by various aspect of the sickness. (8) And patient appreciate the most to be treated with carefully timed and gentled administered honesty. (5)

Finally, to conclude my presentative of needs of terminal patient, I would like to present a case in order to illustrate the actual care that can be done to the patient. In this case, the importance of symptom control, good communication, financial assistance and a few other needs have been shown. This case can be found in Appendix II. (9)

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VI. CONTRIBUTION AND LIMITATION OF MEDICAL PROGRAM TO DOCTOR'S ABILITY IN MANAGING TERMINAL PATIENT

In the previous section, a lot of needs of terminal patient have been presented. But these needs do not seem to be satisfied many a times. Is this the fault of the doctors not doing their job or the environment not allowing them to do it, or rather the medical program does not provide them the necessary education for them to take care of these terminal patient? Now, let me analyse the medical program here and leave other aspects to someone else to evaluate.

In the evaluation of the undergraduate medical program in University of Hong Kong, I discuss it in different formats. Firstly, I discuss the contribution and limitation to a few particular needs of terminal patient as mentioned in the last section. Then I will discuss it in a more general and overall sense.

(i) PARTICULAR

(a) Symptom Treatment

As suggested by all interviewees, there is not much teaching in this aspect of terminal care. And many a times, they do not regard a terminal patient as a patient during their clinical years as they cannot cure them. This might actually have an adverse effect on the doctor's attitude in dealing with terminal patient.

For pain control, what students actually learn is mostly anaesthetic that is geared to the surgical situation but

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have nothing related to terminal care.

(b) Psychological and Social Needs

In this aspect, I found the program both contributes to and limits the doctor's ability. As has been suggested by lot of author's, medical program is actually a dehumanization process which make doctors insensitive to this kind of needs. (10)

On the otherhand, the behavioural science course, which were introduced in the medical program seven years ago, and psychiatry actually make the students aware of this aspect of needs.

In psychiatry, students are being trained to interview the patients and try to get as much information on both psychological state and social background of the patient as possible in order to help him. As commented by one of the interviewees "Pschiatry is the most humanistic specialty among all others".

In behavioural science, the psychological and social aspect of sickness have been taught. Hence students can be more sensitive to this aspect of needs. Interview training is even a sub-course concern about dying patient. All these in a way help the students in a few aspects in the care of terminal patient.

(c) Communication

As observed by Magiure and Rutter (11) that the medical students become less competent in their communication skill

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as they proceed through their medical education, then it seems that the program actually limit the students' ability in this aspect.

However, with all possible adverse effect cause by the program, the communication skill practical provide in the behavioural science course are helpful, (11) which is agreed by interviewees. One practical is actually on the conveying of information to terminal patient.

(ii) GENERAL

There is contradictory view on whether the junior doctors are getting more humanistic or inhumanistic in taking care of terminal patient which reflects the contribution and limitation of the medical program. However, all of the interviewees agree that it is hard to compare the present junior doctors performance to those of years ago because of the changes in the social background of doctor, technological advances, changing in working condition etc. Also, they all agree that the behavioural science course contribute to the doctor's ability to deal with terminal patient and during the clinical years, the education actually have adverse effect on all aspect of terminal care accept psychiatry and community medicine. Community medicine provides medical students a lot of information on the resources they can mobilize for the care of terminal patient, community nursing is a good example and home visiting is another good illustration that community medicine helps students to realize the social aspect of sickness which is of much importance when caring for the

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terminal patient. About psychiatry, I have already mentioned in previous section.

Another important point all the interviewees suggested is that they think the personality of the students is of great importance in the care of terminal patient regardless of what actually being taught in the medical program. For example, the attitude of the tutors in the ward are usually quite inhumanistic, except in obstetric & gynaecology and psychiatry, and this can have difference effect on differenct students. For students who are really concern with the psychosocial needs of the patients, they can learn from this 'negative education' that they should not do it once they graduate, on the other hand, for students who are not concern with the complete care of a patient but rather just cure the disease, they will adopt the attitude of their tutors.

The last point I would like to bring up is that an interviewee thinks the terminal care, accept those of symptoms control, is actually natured to human being and might not require special training. However, I hold an opposite opinion. For instance, in order to help terminal patient to accept death, one needs to understand the fear of death as well and should also be psychologically prepared. (6) Hence, I believe some form of education should be geared to the care of terminal patient. This is also agreed by Dupee (1982).

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VII. CONCLUSION

The terminal cancer patient has many kind of needs. These needs should be provided by a mulidisciplinary team. The undergraduate medical program in the University of Hong Kong both contributes to and limits the doctor's ability in caring these patients. However, I think we should not just look whatthe medical program provide, but also what kind of students being admitted. Are they a bunch of "money-cravers" or people who would like to care for their patients? Also, we should pay attention to the limitation that imposes on doctors by the present medical system. It is quite possible the factors I mentioned above are of more significance than the education program itself in contributing or limiting doctor's ability in caring for their patients.

Finally, doctor is not the only one who is responsible for the terminal patient care. Although doctor is consider to be the centre for mobiliation of available resources for the care of terminal patient, other people such as social workers nurses, chaplain etc, should all join together as a team to provide the complete care on all aspect of needs.

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APPENDIX I

INTERVIEW QUESTION GUIDELINES

1. How do you define 'terminal cancer patients'?

2. By your own observation, what kinds of needs to the patients have?
   - i) Social: (family communication)
     interaction with family numbers and friends
   - ii) Psychological: (acceptance of fate)
   - iii) Pharmacological: (pain killing, for example)
   - iv) Conveying of information:
     to patient and family members
   - v) Family acceptance.

3. What do you think you should do, to satisfy the needs of these patients?
   - i) To help the family members to support the patient
   - ii) To help the patient of accept
   - iii) What can you do, on the physical aspect of the disease
   - iv) How much information should you give to the patient and/or his family members?
   - v) To help the family to accept

4. *Have you ever learned any thing to help these patients in pharmacological aspect?
   - i) Pain killing

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5. *Have you ever learned anything to help these patients in psychosocial aspect?

   i) Social:

   ii) Psychological:

   iii) Team work:

6.**Have you ever done anything to help these patients in pharmacological aspect?

7.**Have you ever done anything to help these patients in psychosocial aspect?

8.**By your own observation, do you find that the yound doctors on the whole possess the necessary skills to deal with the 'cancer patient'?

* Question asked only when medical student is interviewed.

** Question asked only when doctor is interviewed.

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APPENDIX II

垂危病人的照顧：個案研究

聖母醫院
護理法治療組

黃君，五十二歲，一九八二年四月前往廣華醫院看醫生，訴說喉部有腫塊。經過活組織檢驗，證明喉部生癌。他在伊利沙白醫院接受了七個星期的放射治療以後，再進行化學治療。其後，黃君前往大陸看中醫。一九八三年一月，由於健康惡化，他返回本港。他當時非常瘦弱，咽下困難。他由其妻陪同來到本院就醫，因爲其他醫院的探病時間較之本院爲短，她希望有更多時間陪同丈夫。

入院時，黃君蒼白而瘦弱。除了短暫時間坐在床上，幾乎完全臥床。他說話困難，頸部出現一個很大的腫瘤，發出難聞的臭味。他沒有劇痛，但足踝變紅；沒有腫痛或腹水的跡象；大小便失禁。直腸檢查發現有大量稀糞。

醫生告訴黃太說，她丈夫的情形顯然已瀕臨垂危階段，因此治療只能集中在症狀的控制和撫慰方面。醫生又說，醫院中有一個特別小組會協助她侍候她丈夫。黃太感到放心，樂意讓丈夫接受護理法治療。

護理法治療組協調主任在黃君入院後不久探訪他，對他的生理和心理狀況作了詳細的鑑定。其後，又接見了黃太。黃太談到丈夫的患病過程，並且表達了對病情的感想。她談話時，淚流滿面，不僅爲可能喪失丈夫而悲痛，而且害怕面對遭事實。

據她說，丈夫是一個建築工程的「判頭」，讀書不多，但很有責任感和決心。在經濟上，他們尚可應付，四個子女已經長大成人，其中一個是醫科四年級學生。黃君最初選抱着痊癒的希望，後來隨着病況惡化，他變得很平靜，而且很少談到自己的疾病。她的妻子經常安慰他，盡可能在各方面支持他。

辦妥入院手續以後，護理法治療組爲黃君擬訂了治療計劃。他當時最大的問題是頸部潰爛部份發出惡臭。每天三次敷上雙氧水，在必要時吸乾潰爛部位流出液體。變紅的足踝和薦骨對每兩小時一次的翻轉和定時的皮膚護理反應良好。由於改用流質食物，並且伴以小量的雪糕，吞咽的困難從而減輕；黃君對雪糕極爲欣賞。裝置導管以後，小便失禁的情形也告克服。此外，每星期兩次通便，解決便秘問題。雖然他從來沒有呼痛，但護士從他臉上的反應知道他的感覺。詢問他的時候，他只承認情形還不致太差。後來採用慣常的止痛方法，使他感到舒服一點，減輕痛楚。在醫療和護理上，院方採取了一切可行的措施，使黃君痛苦減少。

此外，黃太每天大部份時間都陪伴在丈夫左右。由於他說話日益困難，而且不能提筆寫字，溝通因而特別費時，需要很大的耐心，黃太在這方面提供了不少協助。後來她問協調主任是否需要她爲丈夫盡更多力量。協調主任便安排她協助當值的護士照料她丈夫。黃太爲此感到很高興。

但是，在入院後第四天，黃太聽到她丈夫請求醫生將他轉去伊利沙白醫院的消息，感到很不安。黃君堅持醫生爲他安排轉院，但黃太對聖母醫院的時間和醫療都很滿意，不允讓他轉院。協調主任用了很長的時間協助他們夫婦進行協議。黃君最後表示，他是担心經濟問題。結果一位社工人員到來與他磋商，爲他安排了減費計劃，黃君感到滿意，同意留下。

此事發生後大約兩天，黃君病情迅速惡化。他要求醫生讓他返回熟悉的家居。黃太懇求丈夫留在醫院。但是，黃君很堅決，堅持要回家。黃太不但憂心，而且害怕。她告訴醫生和協調主任，她最担心的是在家裏無法作適當的照料，而且她害怕潰爛的腫瘤會將癌症傳染給其他人。經過醫生和協調主任一再保證院方會給予協助，而且向她解釋癌症不會傳染以後，黃太終於同意接丈夫回家。

在黃君出院回家之前，醫生特別約見了他正在讀醫科的兒子。該青年對父母都很關懷，但他表示自己功課繁忙，無法抽出特別時間在家協助照料。醫生認爲住院費並不是問題的關鍵，但他無法肯定黃君堅持出院回家是否希望在自己的家裏度過生命中的最後幾天。他將這種情形詳細告知黃君的兒子，鼓勵他與父親坦誠交談。醫生同時向他們母子說，他們在家裏會獲得社區護理服務人員的協助。醫生又告訴他們，不論任何時間，任何有關黃君病況的問題，他們都可致電醫院的協調主任。

黃君父子經過磋商以後，兒子留下一張便條給醫生，同意滿足父親的最後願望。黃太在得到護理法治療組和社區護理服務人員給予更直接協助的保證以後，也同意接丈夫出院回家。在出院前，有關人員曾詳細指導黃太如何護理黃君的患部、如何爲他止痛。同時，社區護理服務人員也獲得了有關黃君病情、心理狀態、病歷等的詳細資料。

兩天以後，黃太致電協調主任，說她丈夫陷入昏睡狀態。協調主任表示，如果昏睡是因止痛藥而起，應停止繼續服用。協調主任又建議：若黃太認爲有必要，可以隨時送他返回聖母醫院。

第二天早上，協調主任向黃太了解病況，獲知黃君迴光反照，家人決定讓他繼續留在家裏度過最後的一段時間。黃君在臨終前知道家人陪侍在側，覺得很安慰。

遺體隨後轉送伊利沙伯醫院；黃家的人手持聖母醫院醫生在黃君出院時開具的一封信陪同前往。該信說明黃君患了後期癌症，但經特許出院回家臨終。死後的驗屍手續由此而得以簡化。

葬禮完畢後不久，黃太向院方和護理法治療組表示謝意，感謝他們鼓勵她應允丈夫在家臨終的要求。她同時又感謝他們的實際支持，使他的願望得以實現。另一方面，協調主任又鼓勵她繼續保持接觸。

不久，黃太返回醫院，將黃君生前用過的輪椅送給醫院，而且捐了一筆款項，紀念他丈夫。她一再表示謝意，並且希望本港其他的垂危病人及其家庭都知道病者最後幾天可以接受的療法和服務。

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